



Transverse Myelitis Society Magazine



TM AWARENESS DAY U.K.

With the help of **Lynn Winton (Penny's Mum)**, Penny Winton & George Bowyer invited their friends and family supporters to a swim party at the local swimming pool to celebrate how far they have come, the milestones that have been reached, and to help create more awareness in their community. *Continued on page 5.*

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ANNIE SCHOFIELD

New beginnings are always exciting, so I am delighted to introduce the new Chair of the TM Society to you. The TMS has gone from strength to strength under the guidance of Yvonne Kolesar, and we all owe her a tremendous debt of gratitude. During this time Barbara Babcock has been a Committee member, so is no stranger to the workings of the Society, and I know that everyone was delighted when she agreed to step up. As a Support Group leader myself I look forward to working with her, and fully support her aim to get more groups up and running. For most people, attending a meeting will be the first time they have ever met another person with TM, and they gain so much knowledge by talking to others in the group

TM Awareness Day saw people out in force with some brilliant ideas. I defy anyone not to fall in love with Penny and George, two children with TM who have become firm friends. So much so they decided to hold a joint party at their local swimming pool. You can read about theirs and other events on Page 5. By the way, this may not be the last you have heard of Penny and George.

We always try to include a topic close to your hearts, and this time

it's that bugbear of many TMers, neuropathic pain. We came across Dr. Greenberg's excellent Q & A on the TMA website and wanted to share it with you

I would love to hear your thoughts on Cindy Morelli's article on Page 14. It came about after I had seen the word 'disease' somewhere on the new website. I contacted Cindy and what followed was a very interesting discussion on what's in a name. I get very het up when I see the words illness, or disease, used to describe TM. I think of a disease as something contagious, and an illness as something you recover from. I'm not ill, I just happen to have had an auto immune attack on my spinal cord, end of! Do drop me an e-mail and share your thoughts on this thorny issue and we'll print some of your comments in the next magazine

As you will have seen from previous editions, we do not shy away from tackling sensitive issues, and one that comes up again and again is relationships (and that includes sex). Has your relationship changed with your husband/wife, children – even friends? We would like to address this subject in a future edition, but we can't do it without your input. Your comments can, of course, remain anonymous.

Many of you will be getting ready for the great summer escape, so if I may put my Travel Agent's hat on for a moment – please make sure you have adequate travel insurance. To help you we have put together a list of companies on Page 7 who specialise in insurance for people with pre existing medical conditions.

Here we are already thinking about the next issue of your magazine, which will be our Christmas edition, and we would like to hear from you with your tips for coping with/enjoying the festive season.

Please send in your stories, comments, and suggestions for future editions to me at annie.schofield@myelitis.org.uk

In the meantime, I hope you all have a wonderful summer

Annie

INTRODUCING THE NEW CHAIR OF THE TMS

TRANSVERSE MYELITIS SOCIETY



BARBARA BABCOCK

Barbara Babcock is Chair of the TMS, a professional coach, and consultant in the corporate and charity sectors

I am very pleased to have been nominated and elected as Chair. It was a surprise, but a pleasant one. It is the start of a new journey since contracting TM in October 2008 (two lesions at C4/C5). Since attending first support group meeting in January 2009 in London, I have been active in the TM Society: delivering talks at the London and West Midlands Support Groups, joining the TMS Committee in April 2010, presenting at the 2011 conference, and contributing articles to this excellent magazine. I am excited about the role, and the opportunities and challenges it brings.

Firstly, I would like to thank Yvonne Kolesar for everything that she has done as Chairman during the past four years. The TM Society has benefitted from her passion, commitment, dedication and hard work. Yvonne, you will be missed on the Committee

and I am pleased you will still be a part of the TM Society as the leader for the London Support Group.

I view the Chair role as a custodian of the TM Society. The Society will continue long after my tenure is over. My role is to look after the Society and work with the Committee and membership to build on the good work that has already been done. In doing that, this is what I envisage for the Society. Some of this builds on what is happening now and some is new.

- 1.** Continue to professionalise (as needed) how the Society works (this is often behind the scenes stuff).
- 2.** Continue enhancing communications with support group leaders and members so people feel they have a voice.
- 3.** Continue to be a membership-led charity where members' needs inform the TMS Committee's focus and services the TM Society provides.
- 4.** Support Groups are core to the TM Society, providing much needed and valuable support to the membership. Members, with the support of the TMS Committee and other Support Group Leaders, establish support groups in those areas of the country where there currently are none.

My role is to look after the TM Society and work with the Committee and membership to build on the good work that has already been done.

INTRODUCING THE NEW CHAIR OF THE TMS

- 5.** We run a Kids Camp.
- 6.** We organise regular conferences or mini-conferences.
- 7.** We run fundraising campaigns that yield large donations so that we can expand services for members.
- 8.** We run awareness campaigns among neurologists, GPs, physiotherapists, and other health care professionals to raise the profile of TM. So when someone is diagnosed with TM, she is told about the TM Society. If a person is in hospital and diagnosed with TM, a TM Society member visits him/her.
- 9.** We have a voice in influencing the neurological healthcare agenda in the UK.
- 10.** We fund research.
- 11.** Members have access to neuro-physiotherapy, which greatly enhances rehabilitation.

***We each can take action,
however small it may be, and it
will bring us one step forward.***

- 12.** Members and their families have access to psychological/emotional support to help them have a great quality of life despite the realities of the condition.
- 13.** The TM Society has an advisory board of healthcare professionals.
- 14.** Points 8 thru 13 result in faster diagnosis and treatment, and support recovery and coping.

This is a big list. One person cannot achieve this by him/herself.

My aim is not to achieve all of this tomorrow. It will take time. Longer than my term as Chair, of that I am sure. This list is not exhaustive either. I am sure you have thought of something that is not here (yet). This is what I keep in mind when working with the TMS Committee, Support Group Leaders, and you, our members.

We each have a role in achieving this vision. We each can take action, however small it may be, and it will bring us one step forward. What we can all do includes raising awareness in our local communities, starting a support group, or fundraising to name a few ideas. Whatever you choose to do, it is important and meaningful. It is like a ripple. If we all do something small, those ripples become a wave.

So that you are kept informed of what the TMS Committee is working on, can comment and provide feedback and let us know what you are doing, plus to learn more who your Committee Members are, this 'Message from our Chairman' will change to a 'Committee News' page in the magazine.

If you are interested in helping, please let me know what you would like to do. That will help us match your skills and generosity in giving your time to what needs doing. You can also contact me with questions, comments, suggestions, ideas and feedback at barbara.babcock@myelitis.org.uk.

I am sure I will meet many of you in the future and I am looking forward to that.

MY STORY

TRANSVERSE MYELITIS SOCIETY MARTIN LAMBERT SHARES HIS TM JOURNEY



MARTIN LAMBERT

It was September 2011, ten days before the Great North Run (GNR); I had just completed a hard six mile run. Four days later, I was in Leeds General Infirmary with virtually no feeling in my legs, what felt like tight bandages around my chest and only just managing to control my bladder and bowels.

I struggled to come to terms with what was going on, I had always been fit & healthy and was now helpless, scared and wholly reliant on others. Never having been in hospital in my 45 years, it was a shock to undergo MRI scans, lumbar punctures and within 24 hours of admission treated with steroids, after been diagnosed with Transverse Myelitis (TM).

I went home four days later and was told to take it easy by doctors, family & friends. Routine daily tasks became trials and just walking the ½ mile around the block exhausted me. Even with my determination, the support and encouragement of my family was invaluable. Their love, patience and understanding gave me the strength I needed.

I'm not one to give in easily and after being told that I wouldn't be

running in the GNR, I decided that I'd aim for the 2012 race. With small steps, I started the training, doing my physio exercises & walking unsteadily around the ward, each step being greeted with unbearable pain in my feet and legs.

It was a painful struggle to recover my fitness, but shuffling walks around the block turned into two then four mile walks, and by Christmas I had recovered nearly all of the feeling in my body. I still have pins & needles in my hands but compared to others I'm very lucky.

"I struggled to come to terms with what was going on, I had always been fit & healthy and was now helpless, scared and wholly reliant on others."

January 2012 arrived, new running shoes and the year's GNR ahead. By March I was back to full fitness and running well. Then I found some blood in my urine, TM had taught me to get medical attention quickly. After several tests, which showed no cause for the blood, I found myself in a CT scanner.

I was diagnosed with cancer in my right kidney. Such news is devastating & removes life's certainties - would I see my sons grow up or more immediately would I live to see Christmas.

Lying in my hospital bed after surgery to remove my kidney, I watched the London Marathon and knew that I'd be running it in 2013. Three weeks to the day after surgery I walked 13 miles. Five months later I ran that year's GNR, raising money for the TM Society.

At times the last year has been dark, throughout I was determined to overcome the challenges but without the love & support of my family and friends I'm not sure I could have made it. But here I am in 2013, tingling hands, a huge scar on my right side and about to start my own business. I've learnt to trust others and enjoy life. I'm looking forward with a smile and a new found spring in my step.

TM AWARENESS DAY



TRANSVERSE MYELITIS SOCIETY HOW YOU HELPED TO SPREAD THE WORD

[. .continued from front cover](#)

The children met for the first time in May 2012, when both were recovering from TM in Aberdeen Royal Children's Hospital, both paralysed from the chest down, before the slow road to recovery began. They have some residual issues but not only are they living full lives and participating fully in school life, they have become firm friends

George's dad made a poster entitled 'T.M. Warriors' which was distributed to friends and family via email. There was an inflatable bouncy float to play on and they ended the day with food and a special TM cake, all contributed by family and friends.

Penny, Katie, Emily, Jack, Ellie & Anna had also been on a jewellery making course, and set up a jewellery making group. They worked tirelessly on their project, after school and most weekends. The result was a fantastic selection of bracelets, earrings, bookmarks and key rings for sale on the day.

Lynn 'Just giving' page is now at £732 plus £400+ for jewellery sales We have been blown away!

Neil Pearce 'My employer has been great, allowing me time off for hospital appointments and physio, so, as a thank you, my wife Paula and I decided to do something for the Awareness Day by baking cakes and biscuits and taking them into work. Eight hours in the kitchen and we had 91 muffins decorated with the blue ribbon, and 50 cookies. When we took them into work I was surprised by the generosity of my work colleagues who insisted on donating cash for them, and we raised over £50 to donate to the TM Society.'



Charmain Kember had real reason to celebrate TM Awareness Day. 'It was my two youngest children's christening day. And a very important day to us as our daughter Annabelle (age 4) has ADEM. After the lovely church service it was back to the hall we had hired for our 'after do'. I laid out an extra table and put out a pot of ADEM/TM/NMO/ON wristbands, a small 'donation' jar and ADEM factsheets we had put together and printed off. I am pleased to say we raised £40.85 Just a small thing to do for such a big part of our lives'



Jo Lokwiya of the East Midlands Support Group organised a balloon release.

The balloons were printed and sent from America by her friend Nancy Dute (also a TMer). Jo printed labels explaining what TM is, and on the reverse side the name of the balloon sponsor, together with a name of a person with TM and their date of onset. It is hoped that anyone who finds one of the balloons will read the label!

Jo Gilfillan 'I baked lots of cakes for my friends to enjoy. About thirty people came along. Many local businesses had donated lovely raffle prizes, so we were able to sell plenty of tickets. The event raised £180. Another lady with TM came along with her family and we were able to use the booklets and info to talk about the condition and raise awareness. It was a lot of fun!

ZIP-WIRING? PARAGLIDING?

TRANSVERSE MYELITIS SOCIETY
AN EVERYDAY HOLIDAY
FOR CLARE ROWNTREE



Having recurrent TM is a bit like living a game of snakes and ladders. Just when you've hauled yourself up the ladder from the last episode and managed to come up smiling, another snake bites you on the bum and you find yourself back at the bottom of the rung again. Luckily, I get quite a good response to iv immunoglobulins, but there's still a long period of frustration to overcome before the fun bit starts again of discovering what you can and can't still do with your newly decrepit body.

I've always loved playing in the Alps, so that's where we headed this summer. First up, walking with my lovely new super lightweight walking poles. My arms aren't great, and I'd previously struggled with heavier poles so I could easily justify this latest indulgence. The beauty of walking in the Alps, apart from the obvious, is that everyone walks with poles so you feel less of a prune needing sticks. Also of course, there are the lifts so you can just choose to do relatively flat short walks and still be amongst wonderful scenery and visit the mountain huts for that well deserved beer. Some of the lifts can now even take wheelchairs. It takes a bit more planning when your resources are limited, but I managed some fantastic walking and even did a roped up glacier walk where I could peer into amazingly scary but beautiful crevasses. Sure, I was useless the next day, but it was worth it.

Whitewater rafting is great fun, and the rivers were in fantastic condition when we were there, but we decided that even with optimism I wasn't up to it. We did however discover Hydrospeed,

where you put your arms in a sort of surfer come float, lie down, and surf the rapids. It was brilliant fun! I couldn't really use my legs to steer so they just sort of dangled behind and went where I pointed the nose of the float and as I'd surfed before my TM, I soon found myself out in front with a huge grin on my face! I was useless at stopping as I hadn't the strength, so the instructor caught me with his canoe which seemed to work.

We hadn't intended to go zip-wiring down the mountain, but my husband got climbing with the guys who ran it and they offered us free goes. The start wasn't very elegant as I needed a bit of a helping shove, but it was a good laugh and I loved the sensation of speed which is one of the things I miss since TM.

I wasn't sure that I'd manage paragliding, having watched them running off the side of the mountain to get launched, but my instructor was wonderful, strapped my fold up walking stick onto the harness and with the help of two of his mates who ran by my side lifting me up, we managed. It was unforgettable; calm and serene, just how you'd imagine it would be to fly like a bird. As I would be unable to do the usual landing technique, the instructor had to improvise, but heroically managed to plonk me down on my bum unscathed! He also does tandem flights using a wheelchair contraption and there are even brave wheelchair users who do solo flights using it! If anyone's interested here's his link : <http://www.fly-chamonix.com/en/> Highly recommended!

***“ it's about adjusting your self image,
adapting to the new you and finding your
new capabilities ”***

Yes, there's a sadness and frustration that I can't do what I used to be able to, but there's still lots to do out there, and plenty to go back for next time, whatever level of disability I happen to be grappling with at the time!

For me, recurrent TM isn't the end of the world, but it's a very different world. I'm still able to participate in an active lifestyle albeit at a different level - it's about adjusting your self image, adapting to the new you and finding your new capabilities.

If you're motivated to challenge yourself and see what you can do, 'Sportability' is a charity that offers people with paralysis and neurological conditions opportunities to try different activities and sports free of charge. www.sportability.org.uk

INSURANCE WHEN TRAVELLING ABROAD

Many of you have asked if there are Insurance Companies prepared to cover you when travelling abroad. The following specialise in insuring people with pre-existing medical conditions, but they will all have different policies with respect to TM ADEM, NMO and peoples' own particular circumstances, so it's worth contacting a few and comparing them before parting with your money.

AA Travel Insurance

www.theaa.com/travel-insurance-paid
0845 092 0606
enquiries@aa-travelinsurance.com

Able2Travel

www.ch-facilities.co.uk
0845 839 9345
insure@able2travel.com

Age UK Travel Insurance

www.ageuk.org.uk/buy/age-uk-travel-insurance
0845 600 3348
Use contact form on website

AllClear

www.allcleartravel.co.uk
0845 250 5200
info@allcleartravel.co.uk

En Route Insurance

www.enrouteinsurance.co.uk
0800 783 7245
info@enrouteinsurance.co.uk

Fish Insurance

www.fishinsurance.co.uk
0800 088 3275
Use enquiry form on website

Free Spirit

www.free-spirit.com/
0845 230 5000
freespirt@pjhayman.com

Good to Go Insurance

www.goodtogoinurance.com
0844 334 0160
feedback@goodtogoinurance.com

Holiday Extras

www.holidayextras.co.uk
0871 360 2742

Holiday Services

www.holidayservices.org.uk
01623 557592
info@holidayservices.org.uk

Insure for All

www.insureforall.com
0845 880 0694
Use contact form on website

MoneySupermarket.com

Compare travel insurance for pre existing medical conditions
www.moneysupermarket.com/travel-insurance/pre-existing-medical-conditions/

MS Society Insurance Services

www.mssociety.org.uk
0800 783 3157
mssociety@heathlambert.com

Orbis

www.orbisinsurance.co.uk
01424 215 315
Orbis are specialists in providing Pre-existing Medical Travel Insurance & Life Assurance for people with impaired lives.

Royal Bank Of Scotland Royalties Account Holders

www.rbs.co.uk/personal/current-accounts/g5/royalties-gold.

Saga Travel Insurance

www.saga.co.uk/insurance/campaigns/travel-insurance/travelinsuranceAFF.asp
0800 015 8055

Staysure

www.staysure.co.uk
0845 908 5886
Use contact form on website

World First Travel Insurance

www.world-first.co.uk
0845 90 80 161
info@world-first.co.uk

Travelbilty

www.travelbilty.co.uk
0845 338 1638
enquiries@travelbilty.co.uk

Travel Insurance Web

www.travelinsurancweb.com/pre-existing-medical-condition.htm
0870 033 9985
Use contact form on the website



UNDERSTANDING PAIN IN TRANSVERSE MYELITIS

TRANSVERSE MYELITIS SOCIETY
A Q & A WITH DR.
BENJAMIN GREENBERG



Dr. Benjamin Greenberg, MD, MHS from the University of Texas at Southwestern in Dallas, one of the world's leading experts in TM, has kindly given us permission to reproduce an excellent Q & A he posted recently on the TMA Blog:-

Is pain a typical symptom in conditions like Transverse Myelitis (TM)?

One of the most common issues that people with Transverse Myelitis experience is pain. It can come in many forms, but the most common is a burning or stabbing pain that occurs in an arm, leg or around the trunk. It is often described as a burning, aching or stabbing pain. When the pain occurs in the chest or abdomen it is often described as a squeezing sensation. Frequently the

pain worsens with exertion, stress, heat or in the evening when trying to go to sleep. It is also frequently experienced in an area that had previous sensory changes. This type of pain is often not present at the onset of TM, but develops in the weeks or months afterwards.

What is neuropathic pain?

Medically, there are many types of pain that affect human beings. Neuropathic pain occurs when there is damage to a part of the nervous system and after that event normal sensation is replaced with uncomfortable sensations.

" While a person's foot may burn at night, there is no flame near the skin! So why does the brain perceive pain? "

Why is neuropathic pain experienced in neuro-immunological conditions?

Neuropathic pain has a different cause, and treatment to other types of pain. When you place your hand on a hot stove, it hurts. It is supposed to hurt. A signal moves from your hand to your brain and is interpreted as pain. The wound is painful even during the healing stages. This process is there to protect animals from tissue injury. We are supposed to learn that placing hands on hot stoves is dangerous! The medications used to treat this pain include opiates because the brain's pain centres have large numbers of opiate receptors. When opiate medications bind to these receptors it dampens down the perceived pain. As the medication wears off, the pain returns. In reality, the pain signals are always there – transmitted from the wound to the brain, but are ignored by the brain when opiates are present.

Neuropathic pain is different. Very different! While a person's foot may burn at night, there is no flame near the skin! So why

UNDERSTANDING PAIN IN TRANSVERSE MYELITIS

TRANSVERSE MYELITIS SOCIETY
A Q & A WITH DR.
BENJAMIN GREENBERG

does the brain perceive pain? The answer has to do with the pain pathways to the brain and pain centres in the brain. When sensation fibres in the spinal cord are damaged by Transverse Myelitis there is often a loss of normal sensory input to the brain. As a result, the sensation networks in the spinal cord and sensory centres in the brain are left with incomplete input of signals. The brain is used to receiving billions of signals every second from our bodies. Temperature, vibration, pressure, movement, light touch and pain inputs bombard our brain constantly. Every square inch of skin includes thousands of nerve endings responsible for a multitude of signal types. If the pathways responsible for vibration are damaged in the spinal cord, then the brain receives an incomplete “sensory picture” about what is happening to the feet. The spinal cord is left to manage incomplete sensory inputs. As a result of these changes the spinal cord can lead to amplification of some sensations (in an unpleasant fashion) and the brain can “fill in the gap” of missing sensation with unpleasant sensations (burning, squeezing, stabbing pains).

“While at work or busy, people may not experience the pain, but when less distracted, their brain may be free to ‘make things up’”

Why does neuropathic pain get worse at night?

Many patients indicate that their pain is worse in the evening when trying to go to sleep. You may wonder why this occurs! As the brain “fills in gaps” you might expect distraction to lessen this phenomenon. Thus, while at work or busy, people may not experience the pain, but when less distracted, their brain may be free to ‘make things up’! Just as a person tries to relax, their brain kicks into gear and the pain intensifies.

What are common treatments for neuropathic pain?

Neuropathic pain is not supposed to be there – no damage to the affected area exists. Rather, the damage is in the nervous system carrying signals from that area. As such, the treatment for this type of pain would be expected to be different to the treatment of other types of pain.



Treatment of neuropathic pain usually does not involve opiate painkillers. Often patients with neuropathic pain will say that the use of opiates ‘took the edge off’, but did not rid them of pain. As such we usually use antidepressant or antiepileptic medications to treat neuropathic pain. Are patients depressed or having fit? NO! These classes of medications act on cells in the brain and spinal cord to dampen down the ‘made up’ signals that are interpreted as pain and as such are perfect for neuropathic pain. Examples include amitriptyline, Pregabalin, gabapentin and carbamazepine. There are many other options that have been used in patients. Beyond medication, many patients will find benefit from topical anesthetics to reduce all sensory signalling, acupuncture and/or avoidance of pain triggers. A careful discussion with your doctor about your pain is needed to discuss what it feels like, what triggers it, what has helped in the past and what medications might be indicated. Pain needs to be aggressively treated as it can worsen mood and energy levels. Often multiple agents need to be attempted so that an appropriate one can be found.

THANK YOU FOR YOUR SUPPORT

Thank You

TRANSVERSE MYELITIS SOCIETY
MORE FUNDRAISING
STORIES

Andrew Hinder has been there, done that - and got the T shirt!

A sportive is a non competitive recreational mass cycling event. It's a modest achievement for a fit adult to complete, however at the age of 63, and with three years of TM behind me, I am quietly proud I completed the short course in the Wight Riviera cycle sportive on Sunday 19th May. Bradley Wiggins has nothing to fear from me, but I climbed strongly on long Isle of Wight hills, and for the record I did the 62km in 3hrs 11mins., finishing half way down the field of 63 riders for this distance.



In May 2010, when I first experienced the full set of TM symptoms, I really didn't think that I would be capable of any sport ever again (until then I was an active runner in a local running club). I still can't run, but I visit the gym regularly to stretch and exercise. I also go cycling of course, but an essential part of my recovery programme has been regular neuro physiotherapy. It has increased my mobility and strength dramatically, and without it I would not have been able to participate in the event.

So far he has raised over £535, well in excess of his target of £360

Bhupinder Sidhu (also known as 'Sid'), Treasurer of the Telford Support Group, organised a charity football match between England and Wales which

took place at the Millenium Stadium in Cardiff on 14 May. "We had a great turnout of around 280 people. There was a great

atmosphere and everyone said they thoroughly enjoyed the spectacle. The downside was that England threw away a 4 - 0 lead to lose 5 - 4 !!! Never mind we will win it back next year!

They raised over £1500 for the TMS

Thank you to everyone who has raised money, we're sorry if we haven't had room to mention you, but your efforts are hugely appreciated



Peter Henderson and five friends, all wearing blue t-shirts and blue ribbons, competed in the Ythan multi-terrain 12km adventure race on 16th June. Peter is a close friend of the Winton family, so wanted to do it for Penny, and to raise awareness of TM. They have raised over £500 to date.

Anita Thandi of Kent competed in the gruelling Three Peaks challenge on 1-2 June in recognition of the support she received from the TM Society when a relative was diagnosed with NMO.

If someone is doing a fundraising activity for the UK TM Society, did you know they get a free t-shirt for as a thank you for their efforts? Ideal for wearing during training and/ or on the day of the event itself. Just send the size t-shirt you want together with your address to barbara.babcock@myelitis.org.uk. You can also purchase t-shirts at a cost of £15 each (this includes postage).



My name is Suzanne Carr and I have had TM since 1979. As part of our fight to promote 'TM awareness', I have decided to sell TM bracelets, phone and bag charms. My friend Rachel has offered to make them, with a donation from each one going to the Transverse Myelitis Society, here in the UK. Each item is handmade so no two will be exactly the same, in fact they will be as unique as us! Costs are from **£2.00 to £5.00** inc. delivery to UK addresses. Initially, female and child bracelets will be offered with the option of a male version in the future. Please email me at **Carrs39@hotmail.com** to see what's in stock.

The Cinema Exhibitors' Association card verifies that the holder is entitled to one free ticket for a person accompanying them to the cinema. It costs £5.50 and is valid for a year. You need to be in receipt of DLA, PIP or Attendance Allowance. Full details can be found at **www.ceacard.co.uk**

The Radar Key Scheme

The National Key Scheme (NKS) offers disabled people independent access to locked public toilets around the country. Toilets fitted with National Key Scheme (NKS) locks can now be found in shopping centres, pubs, cafés, department stores, bus

and train stations, and many other locations in most parts of the country.

The National Key Scheme Guide 2012 has the location of the 9,000 accessible toilets across the UK fitted with the NKS lock. This valuable resource is the only guide of its kind and really does open doors to independent living. Information can be found at **www.radar.org.uk**

The Radar NKS key costs £2.25, plus £1.75 Postage



TMS reaches out

The TM Society would like to expand the opportunities people have to reach out to others in their area for support, friendship, to share stories and advice, and to know that they are not alone. And we are aware that in some parts of the UK there are no support groups. Who knows, there could be someone living not far from you who also lives with TM/ADEM/NMO, whether they are affected themselves or are a carer.

If you want to share your email address with others local to you so you can meet up, private message me with your email and where you live (or email me at **barbara.babcock@myelitis.org.uk**).

I will then send an email to those who've responded 'yes' with a list of your names, email addresses and the town where you live so you can start getting in touch with one another.

Barbara Babcock Chair, TMS

Our facebook page now has nearly 500 members! It can be a useful and relatively informal way to reach out to other members to ask for advice and tips on dealing with whatever is bothering you. This can lead to some lively debates. More importantly, it is a closed group. Search for Transverse Myelitis Society on facebook.com to join

find us on
facebook





The Sequela Foundation was founded in 2011 by Pat Capp and gained charity status in August 2012 after a lot of hard work fund raising. It was set up as a non profit making organisation and offers a support network, therapies and socialising to anybody who has any kind of neurological condition in the East Berkshire area.

Pat Capp has worked in the fitness and swimming industry for over 30 years. Well known in the local area, she has run a highly successful Swim School for over 33 years. She has taught over 250,000 children and adults alike to swim, and was the first person to introduce Water Exercise Therapy to the UK from the USA, setting up many classes for able bodied and disabled alike. She then trained as a Pilates teacher about 15 years ago, sharing her knowledge of improved joint, muscle, and mobility, to thousands of people. She also lectured in the States on the importance of exercise in the young.

In 2006, Transverse Myelitis struck, and Pat was paralysed from the neck down. With her knowledge of exercise, and the importance of it, she gave herself a strict regime of daily exercises as an integral part of her recovery phase.

In spite of having recurrent attacks of TM, each time Pat has got back on her feet. Tough as it has been, and despite her ongoing TM episodes, she found the initiative, energy and drive to set up and run the Sequela Foundation for the benefit of others affected by neurological illness, building a successful team around her.

The Therapy Centre offers help in two ways by providing a wide range of physical therapies including massage, reflexology and Pilates based exercise, yoga, and Qigong. Importantly it is also a social hub and networking centre to learn about other life-enhancing skills, counselling, art, gardening, local history and photography for example. Combined, these two areas deliver significant benefits and improved quality of life to both those living with a neurological condition and their carers.

In January this year the Sequela Foundation opened their own premises and is thriving, with their membership growing weekly. The centre is entirely financed by fund raising events and donations from a variety of sources. The centre, the first of its kind, was officially opened in March by The Rt Hon Theresa May, who immediately recognised the importance and benefits of the centre, and was full of praise for the volunteers and for Pat's tremendous achievement.



“Have your say”

Bounced

My son Joe is 24 and contracted TM 4 years ago and has a lesion between C5 & C7. The right side of his body is affected and has sensory impairment, his legs become very stiff even after a short distance, and there is a sudden noticeable difference in his hip and walking. The reason I'm writing to the magazine is to ask if you could run an article to see if other TM sufferers have experienced any form of discrimination from 'Bouncers' at the entrance to nightclubs.

Joe has been refused entry on various occasions when he has been out with his friends, the security have accused him of being drunk because of his walking. He has a letter from his GP to clarify his condition but this has not always helped, the Bouncers have even refused to look at the evidence. He doesn't go out that often since having TM. Obviously you find out who your real friends are, and some do not bother anymore, but since being refused entry to several clubs he has lost the confidence to even attempt going out with his mates. I have had to go out and collect him on occasions because the group he is out with have gone into the nightclub and he has been left on his own. It breaks my heart that he has been treated like this and after reading the magazine I thought it would be interesting to hear if this is common in any other area. If he was in a wheelchair these Bouncers would not be so brave, but because apart from his walking you might not notice the other symptoms, they think they have the power to discriminate.

Corine Garrod

Addendum: Ministry of Sound

(who we must stress were **not** the nightclub in question) have kindly offered Joe and 5 friends 'free admission, table and first round of drinks' to show that not all nightclubs/bouncers are bad!

*If you have had a similar experience with 'jobsworth' people being unsympathetic to your condition please write and tell us about it. **Editor***

Travel Insurance

Here's a question you may have been asked in the past, but I am sure the answer will interest a lot of TM people.

Travel Insurance – is there a specific company who specialise in travel insurance cover including medical (at a reasonable rate) for people with TM ? **Barbara Teixeira**

*Many of you have asked this question, and, with thanks to Margaret Shearer for her help, we hope the information on page 7 is of use. **Editor***



Send your letters and views, ideally no more than 200 words in length, including contact address and phone number, by email to:

annie.schofield@myelitis.org.uk. N.B. Letters may be edited.



CINDY MORELLI *first became involved with the TMS when she helped to organise the Conference in Wyboston in April 2011, and joined the Committee just after that. Since then her main focus has been the new TMS website.*

A couple of issues ago we had an article on disabled toilets by Ruth Wood, who pointed out the irony of the name. Surely, she said.... 'a 'Disabled Toilet' was one that had been taken out of service because it didn't work'. I was amused by this, but the mis-terminology does no harm.

Sometimes, however, names do have implications. When I see the words 'TM sufferer' used to describe someone with TM, it's like a red rag to a bull for me. It's not that I'm keen on political correctness, it just feels like it re-enforces an idea that TM is running this person's life.

Last summer I trained to become an Expert Patient Programme tutor. We were coached to avoid referring to people with conditions as 'ics' (diabetics, epileptics, schizophrenics, etc). In the medical world, the label is a short hand of a person with a condition, but in ordinary life, we are talking about a person who has or is living with epilepsy or diabetes. The condition shouldn't be used as a short-hand of who they are. We were also told to avoid using

the terminology of a 'whatever-the-condition sufferer'. Using the words 'TM sufferer' to describe someone with TM is implying that TM defines the person. At first I thought that avoiding the 'ic's' was a bit subtle, but the more that I heard people use 'sufferer', the more convinced I became that labelling someone as a TM Sufferer is re-enforcing them as a victim. Thinking of yourself as a victim is not conducive to making progress or feeling happier!

If you attend support group meetings, one of the things that you will see over and over is people describing their TM journey. At the beginning, TM has control. The person reels through the perplexing, frightening and life-changing moments that take up the initial days, weeks and often months. At some point though, the person with TM comes to accept the reality of their situation, they reclaim themselves, choose to change what they can, work with what they have and they become a person living with TM. The person takes charge of their situation and they just feel better.

Positive affirmations feature in most self-help material, 'mindfulness' and many other types of therapies. Whether they work for you or not is an individual matter. One thing that I am absolutely certain of, however, is that using a negative affirmation like defining yourself as a 'TM sufferer' can't be doing any good!! That doesn't mean we have to avoid negative words. People do suffer from TM, but that is different to using a tag of 'TM sufferer'.

If we aren't TM Sufferers, what do we call ourselves? Looking through past magazines, the name that stands out most often is 'TM-er'. How does that make you feel? Personally, it makes me feel that I am part of a unique group of people with a shared rare experience – quite a positive feeling really.

Do you have your own pet hates? My personal ones are illness and disease – surely a disease is something contagious and an illness is something you recover from. Drop us an email and share your thoughts on what's in a name and we'll print some of your comments in the next magazine. Editor

NEWS FROM THE UK SUPPORT GROUPS

TRANSVERSE MYELITIS SOCIETY
FIND OUT WHAT'S HAPPENING
AT A SUPPORT GROUP NEAR YOU

NORTH EAST SUPPORT GROUP

SUPPORT GROUP MEETINGS ARE: ***THE FIRST SUPPORT GROUP IN THE NORTH EAST IS ON SATURDAY 27TH JULY 2013 AT 1.30PM***

Venue: Walter Best Hall (within Cornerstones), Chester-le-Street Methodist Church, North Burns, Chester-le-Street, DH3 3TF
www.cornerstonescentre.co.uk. Cornerstones is situated in the centre of Chester-le-Street and has full disabled access including provision of Changing Places facilities for people with severe disabilities.

Directions

From the A1(M)

Follow the signs for A167 towards Durham. At the first roundabout take the 2nd exit towards the town centre. At the mini roundabout, go straight across towards the Market Place. The church is on the corner and the entrance to Cornerstones is via the ramp on the front left hand side

From A167

Follow the A167 north towards the A1(M) initially ignoring directions to the town centre/Chester-le-Street. At the roundabout next to the Total garage (last roundabout before the A1(M)) take the first next sharp left towards the town follow directions 3 & 4 above.

From Chester le street Train Station .4 miles

Car Parking

Car parking is available within the town at a rate of £1.10 per day indicated by the P on the map.

For further details: Contact Margaretshearer@myelitis.org, phone 01292 476758 or 07968 461156

EXETER SUPPORT GROUP

SUPPORT GROUP MEETINGS ARE: ***THE FIRST MEETING WILL BE ON 6TH OF JULY 1.00 TILL 3.00. A FURTHER MEETING IS PLANNED LATER IN THE YEAR, THEREAFTER IT WILL BE QUARTERLY.***

Venue: Holiday Inn Express Exeter, Guardian Road, Exeter EX1 3PE The meetings will take place in the main reception area.

For directions go to: <http://supportgroups.myelitis.org.uk/exeter.html> For further details contact Rob Reeves rreeves@myelitis.org.uk

LONDON SUPPORT GROUP

SUPPORT GROUP MEETINGS ARE: ***13 JULY, 26 OCTOBER AND 18 JANUARY 2014***

Dr Joan Hester will be our guest speaker on July 13th. She is a Consultant in Pain Medicine at King's College Hospital, London, and a Past President of the British Pain Society. Those of you who came to the 2011 Conference may well remember her invaluable talk on pain management. I know that she will be very willing to answer any questions you might have.

Venue: ECHQ, 34 York Way, London N1 9AB. The venue is wheelchair friendly, and car parking is FOC from 1.30pm on Saturdays in York Way. There is no London Congestion Charge on Saturdays. We are a short 3-4 min walk from King's Cross Station. For further details contact Yvonne Kolesar Yvonne.Kolesar@myelitis.org.uk, Tel. 01737 552869

NEWS FROM THE UK SUPPORT GROUPS

TRANSVERSE MYELITIS SOCIETY
FIND OUT WHAT'S HAPPENING
AT A SUPPORT GROUP NEAR YOU

SOUTH EAST SUPPORT GROUP

SUPPORT GROUP MEETINGS ARE: **14 SEPTEMBER & 07 DECEMBER (CHRISTMAS LUNCH) AT 2.00PM**

In September Debbie Weller will be talking about how to raise concerns and complaints about NHS care, then the new TMS Chair, Barbara Babcock, will tell us what the committee is working on, and giving you the opportunity to ask questions.

Venue: Pembury Village Hall, High Street, Pembury, Kent TN2 4PH. It is wheelchair friendly with disabled toilets. There are 2 disabled parking bays and 10 further parking places outside. Additional parking on the road. For further details contact Annie Schofield annie.schofield@myelitis.org.uk, Tel: 01435 864 662, Carol Preece preece.carol@googlemail.com, or Peggy Hughes mail@peggyj.com

POOLE/BOURNEMOUTH SUPPORT GROUP

SUPPORT GROUP MEETINGS ARE: **20 JULY & 19 OCTOBER**

Venue: We now have a new venue, The Multiple Sclerosis Society Bournemouth Branch, The Osborne Centre, Church Lane, West Parley, Ferndown, Dorset, BH22 8TS For further details contact Group Leader: Lance Harris, lv.harris@hotmail.com or Secretary: Barbara Houston 01425 673173 barbs@houston19.freemove.co.uk

BRISTOL SUPPORT GROUP

SUPPORT GROUP MEETINGS ARE: **01 SEPTEMBER & 01 DECEMBER**

Venue: The Reception area of the Holiday Inn, north Bristol. For further details please contact Steve Collins, steve.collins@blueyonder.co.uk

EAST MIDLANDS SUPPORT GROUP

NEXT SUPPORT GROUP MEETING: **12 OCTOBER**

Venue: The Village hall, Lullington, Nr Swadlincote. DE12 8EG. For further details contact Janet Ashenden, jan.nig@tiscali.co.uk

TELFORD SUPPORT GROUP

SUPPORT GROUP MEETINGS ARE: **18 JULY & 19 SEPTEMBER NEW TIME 18:00-20:00**

Venue: Ketley Community Centre, Holyhead Road, Ketley, Telford, Shropshire, TF1 5AN. The venue is wheelchair friendly with easy access. For further details please contact Anna Paulsson-Habegger on 07581708597 annaph@blueyonder.co.uk

TRANSVERSE MYELITIS SCOTLAND

NEXT SUPPORT GROUP MEETING: **28 SEPTEMBER & 23 NOVEMBER AT 2.00PM**

Established in 2003, we have over 90 Scottish members and the group is open to all patients with TM and its associated conditions living in Scotland, and to their families, carers and friends. The group is a member of The Neurological Alliance of Scotland, Long Term Conditions Alliance Scotland, registered with The Towpath Trust, The Princess Royal Trust for Carers and NHS24.

Venue: Conference Room, Philipshill Ward, Spinal Injuries Unit, Southern General Hospital, 1145 Govan Road, Glasgow G51 4TF
Dates of our meetings are posted on our webpage www.myelitis.org/scotland and travel directions can be seen by clicking on the Events link. For any further details contact: Margaret Shearer on 01292 476758 or email margaretshearer@myelitis.org

USEFUL CONTACT INFORMATION

Bladder & Bowel Foundation

0845 345 0165

www.bladderandbowelfoundation.org

Brain & Spine Foundation

0808 808 1000

www.brainandspine.org.uk

Carers Direct

0808 802 0202

www.nhs.uk/carersdirect

Carers: The Princess Royal Trust

0844 800 4361

www.carers.org

Continence Foundation

www.continence-foundation.org.uk

info@continence-foundation.org.uk

Depression Alliance

0845 123 2320

www.depressionalliance.org

*Disability Information
Advice Line (DIAL)*

01302 310 123

www.dialuk.info

Disability Law Service

0207 791 9800

www.dls.org.uk

Disabled Living Foundation

0845 130 9177

www.dlf.org.uk

Disability Now Magazine

01454 642 444

www.disabiltynow.org.uk

Driving: Disabled Motoring UK

01508 489 449

www.disabledmotoring.org

Driving Licences:

DVLA Drivers Medical Unit

0870 600 0301

Gardening

www.gardeningfordisabledtrust.co.uk

Mobility aids: Just Mobility

01923 265 577

www.justmobility.co.uk

Motability Car Scheme

0845 456 4566

www.motability.co.uk

*Neuromyelitis Optica (NMO)
[Formerly Devics Disease]*

www.nmouk.nhs.uk

*NMO: The Walton Centre, Liverpool
Nurse Specialist*

0151 529 8357

NMO Service Coordinator

0151 529 8131

nmo.advice@thewattoncentre.nhs.uk

*NMO: John Radcliffe Hospital, Oxford
Nurse Specialist*

01865 231 905

NMO Service Coordinator

01865 231 900

nmo.advice@orh.nhs.uk

Pain Concern

0300 123 0789

www.painconcern.org

Pain: British Pain society

0207 269 7840

www.britishpainsociety.org

*Welfare & Disability Benefits
(Dept. of Work and Pensions)*

0800 882 200

www.dwp.gov.uk

Transverse Myelitis Society

35 Avenue Road

Brentford TW8 9NS

www.myelitis.org.uk

U.K. registered charity 1108179

Contact Barbara Babcock

(chair) barbara.babcock@myelitis.org.uk

Lew Gray (Secr) 020 8568 0350

Email: lewgray@blueyonder.co.uk

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